

How does mobility interrupt engagement and retention in HIV care and treatment among women in Kenya? An exploratory study

ABSTRACT

This study explored barriers to engagement and retention in HIV care and antiretroviral therapy (ART) programs faced by HIV-infected internal migrants, specifically highly mobile women, in a high HIV prevalence area of Kenya, where previous studies also documented high levels of localized mobility undertaken by both men and women^{1,2}. Kenya is rapidly expanding its ART programs, but faces numerous barriers to progress. Recent studies of patient retention in ART programs reported rates ranging between 64% and 81% after one year³. Few studies have explored how mobility affects the ability of HIV-infected individuals to engage in care, nor how their mobility affects the success of ART once engaged⁴. Preliminary findings from in-depth interviews with 15 HIV-positive women in Kisumu suggest that mobile women travel to obtain HIV care in order to avoid stigma and disclosure in home communities, but miss appointments and interrupt treatment because of distance to clinics and travel schedules.

STUDY OVERVIEW

This study explores the barriers to engagement and retention in HIV care and treatment faced by highly mobile women in western Kenya. The study was conducted in Nyanza Province, Kenya, which faces a severe, persistent HIV epidemic, with a 15.4% prevalence that is double the national average⁵. In Kisumu, the provincial capital, 25% of women in Kisumu were HIV-infected in 2009⁶. HIV incidence is especially pronounced in the population living in the beach villages along the Lake Victoria near Kisumu; an estimated 26.2% of new infections occur in these communities⁷. Previous studies in Kenya have found high levels of participation in migration by both men and women^{1,2} and higher sexual risk behaviors among migrants than non-migrants¹. Our prior research in the setting found that highly mobile women in the Kisumu area were at high risk of HIV acquisition and transmission: the circumstances that drove migration may have also increased HIV infection risk at origin; and social contexts in destinations facilitate having multiple sexual partners and engaging in transactional sex^{8,9}.

In Kenya, a national rollout of anti-retroviral therapy (ART) programs for HIV-infected patients is underway. However, the nation faces major challenges along the so-called “treatment cascade”, with gaps in testing, enrollment and retention in care, and initiation and adherence to ART. HIV testing rates among women remain low: in 2008-09, 30% reported they had ever been tested and received results¹⁰. Only 60-80% of those diagnosed are retained in ART programs in Kenya after one year³. The reasons for attrition remain under-researched³, and very little attention has been paid to how mobility affects the ability of HIV-infected individuals to engage in care, nor to how their mobility affect the success of ART once engaged⁴. This is especially so for mobile HIV+ women, a neglected population in HIV research. This study’s aims were:

1. To explore the ways in which women’s mobility impacts upon their ability to enroll, remain engaged in HIV care, and adhere to ART regimens; and
2. To identify factors at multiple levels and domains (psychological, social, environmental, cultural and economic) which present barriers to, or opportunities for improving, mobile women’s access and retention in care, and could serve as potential points of intervention.

We selected a sample of 15 highly mobile women using theoretical sampling techniques¹¹ from high mobility settings in the Kisumu area in which we carried out ethnographic mapping, participant observation, and qualitative interviews with highly mobile women in a prior research study on patterns of mobility and HIV risks among female internal migrants in western Kenya. This study recruited women who, in that study voluntarily self-reported their HIV-positive status and agreed to participate in this follow-up study to explore their experiences with and relationship to HIV care and treatment programs. Thus, two in-depth semi-structured interviews were conducted with each participant: the first interview involved an in-depth exploration of women’s mobility patterns, migration histories, household arrangements and sexual partnerships, livelihood strategies, perceptions of HIV risk, and experiences with HIV testing and disclosure. The second interview, for this study, focused on several domains of inquiry concerning how women’s mobility affected their engagement and retention in care, and adherence to ART regimens, as well as other factors affecting their engagement in HIV care programs and ART.

BACKGROUND

Challenges in engaging and retaining HIV+ women in care. Kenya faces major challenges in its efforts to expand access to ART for its HIV-infected population. In 2008-09, only 30% of women of reproductive age reported they had ever been tested and received results¹⁰. In 2006, the National AIDS Control Programme estimated that only 40-50 percent of

all HIV-positive pregnant women were accessing prevention of mother-to-child transmission services¹². ART programs in Kenya lose contact with patients after they officially transfer to another clinic; thus “retention in care” may be substantially higher than “retention in clinic”¹³, although difficult to measure due to limited data linkages across programs. Other patients drop out of care completely (“default”), or are “silent transfers” to other ART programs; in the latter case, how women subsequently present themselves at other clinics (i.e. whether they disclose their status or are tested anew, choose to communicate about their treatment regimen and can do so clearly) is largely unknown. Six studies of patient retention in antiretroviral therapy programs in Kenya in the years 2003, 2006 and 2007 reported retention rates ranging between 64% and 81% at 12 months; one study with a 24 month follow-up reported 66% retention in care³. The reasons for loss to follow-up (i.e. the major cause of attrition, other than death) remain under-researched³, especially in resource-limited settings¹³, but a recent review¹³ highlighted socio-structural barriers to retention such as provider and program characteristics, distance to clinic and lack of transportation, poverty/ financial constraints, work/child care responsibilities, and issues of social support, stigma and disclosure. Adherence to ART regimens is known to be difficult even among patients in resource-rich settings, due to factors such as the complexity of the regimens, side effects, HIV-related stigma, and competing priorities and demands¹⁴.

Consequences of inconsistent engagement and poor retention in care. For patients on ART, staying actively engaged in clinical care, and adhering to ART, is critical to living a longer, healthier life; retention in care also provides additional benefits through social support, prevention messages and other ancillary services. Inconsistent engagement and retention in care (as measured by appointment-keeping over time) has been associated with death in HIV+ adults¹⁵. Effective ART regimens promote viral suppression, which reduces the chances of HIV transmission to sex partners; and disruptions in the regimens can result in the emergence of drug-resistant virus. For individuals, initiation of ART early in the disease process and adherence to therapy are the most effective interventions to increase survival; at the population level, ART is now seen to be an important component of secondary prevention.

Little is known about the impact of women’s mobility on care and treatment outcomes. The links between population mobility and HIV risks are well-established, but little attention has been paid to how mobility affects the ability of HIV+ individuals to engage in care, nor to how their mobility affects the success of ART once engaged⁴. A Canadian study found that migration adversely affected ART adherence¹⁶, but to our knowledge, no similar studies have been carried out in resource-poor settings. The lack of standard definitions of mobility is cited as a contributing factor to the dearth of research on the HIV care needs of geographically mobile populations in general⁴, but gender biases in definitions of mobility, data sources, and research practices (as documented by Hugo¹⁷ and Bilsborrow¹⁸, among others¹⁹⁻²¹) have also contributed to a paucity of research on the HIV prevention and care needs of female migrants in particular²².

DESIGN AND METHODS

This study was carried out in a subsample of 15 HIV-positive women from a “parent” study of the social and psychological factors that facilitate HIV risks among migrant and highly mobile women in the Kisumu area of Nyanza Province, Kenya. In that study, 35 female participants were recruited using theoretical sampling techniques¹¹ from key migration destinations within the Kisumu area in which the research team had carried out ethnographic mapping, participant observation, and preliminary in-depth interviews. The theoretical sampling categories for the study were derived using data from a pilot study conducted by the investigator and research team

members in 2009-10: major typologies of migrant and highly mobile women in the setting include rural beach-based fish traders, market-based traders, and “house helps”, or domestic workers in urban Kisumu estates. The team also sought age diversity in the sample, which also proxied for diversity in marital status and household composition. Women were eligible for the study if they met the study criteria for “migrant” or “highly mobile”: for this study, **mobility** was defined as traveling regularly and sleeping away from the home area for the purpose of earning income at least twice per month, and **migration** defined as a change of residence as an adult over state, province or district boundaries, excluding moves undertaken for the sole purpose of nuptiality (as migration for marriage is common among women in Kenya).

In the parent study, in-depth semi-structured life history¹¹ interviews were conducted to elicit women’s narratives of their lives as migrants. A trained ethnographic interviewer followed a semi-structured interview guide designed to elicit women’s articulations about their history of migration and current patterns of mobility; the events that led up to and reasons for their decision to migrate, including structural and household-level gender inequalities at the point of origin; their current relationship and household arrangements; their economic activities and social relationships; their sexual relationships, and perceptions and beliefs related to HIV infection and transmission risks; and their appraisals of stressful life events and daily hassles, their coping efforts, perceived social support and resilience/long-term morale. The interviewer also allowed participants to digress from these topics to discuss salient subjects with analytical value for this study. At the end of the interview, women who voluntarily disclosed their HIV seropositive status were then invited to participate in a follow-up interview for this study, which explored their experiences with HIV care and treatment. The same interviewer conducted the follow up interview, permitting both interviewer and participant to refer to experiences discussed in the first interview.

Both studies were reviewed and received institutional approvals from the Committee on Human Subjects Research at the University of California at San Francisco (UCSF CHR) and the Ethical Review Committee of the Kenya Medical Research Institute (KEMRI ERC). The in-depth interviews were conducted over January through June 2013, in private rooms at Lumumba Hospital in Kisumu. The interviews were carried out in the language of the participants (Dholuo or Kiswahili). Digital recordings of the interviews were transcribed and translated to English, and imported into Atlas.ti²³, a qualitative analysis software program. Analysis of the data is currently underway, and is being conducted by a team including the Principal Investigator, Co-Investigators, and the ethnographic interviewer. The process of data analysis involves iteratively analyzing interview texts and developing a common set of codes describing patterns observed in the data. New codes proposed by research team members are vetted and defined in relation to existing codes. The research team members are independently coding the interviews and discussing data segments that are particularly rich or difficult to code. We are discussing and resolving divergent coding and interpretations of findings, and are developing analytical memos summarizing findings following the domains of inquiry for the study, as well as from unexpected but salient topics emergent in the data.

EXPECTED FINDINGS

Preliminary analyses of the data suggest that highly mobile women such as market traders may take advantage of their travel away from home communities to obtain HIV care in distant settings, in order to avoid HIV-related stigma and disclosure in home communities; but they but miss appointments and interrupt treatment because of distance to clinics and travel

schedules. However, some typologies of migrant women, e.g. “house helps”, who are often younger women either orphaned or from destitute households, sent from rural areas to work in Kisumu, have difficulty accessing HIV care and treatment because of their work-related constraints: their freedom of movement is often restricted, time off is rare and risks of disclosure of their HIV status in the households in which they work compell many to forego seeking regular care and treatment. As we continue to analyze the data, we expect the findings of this study to be organized according to the domains of inquiry outlined in the table below:

Domains of inquiry & research questions
<p>Highly mobile women: mobility processes, engagement and retention in care, and adherence</p> <ul style="list-style-type: none"> • Do women access one main clinic, attending it when they are at ‘home’, or circulate between more than one? What is their reasoning for whichever strategy they follow? How do they learn about HIV services at temporary destinations? • Have they changed care programs because of mobility? If they currently or in the past have changed ART programs, how have they presented themselves at the new clinic? • How does mobility affect their ability to make appointments and adhere to treatment regimens? • For those engaged in care, how has it affected their mobility? To what extent does it result in improved health status to the extent that women who were ill and taking a hiatus from livelihood activities involving mobility (e.g. long-distance trading) resume these activities? • What would make it easier for them to access and remain in care in all locations?
<p>Migrants: migration processes, engagement and retention in care, and adherence</p> <ul style="list-style-type: none"> • How do they present themselves for care in destinations: do they present with transfer letters, inform clinicians about prior treatment regimens, or are they tested anew? How do they learn about HIV services? • What motivates them to engage in care? What inhibits them from accessing care? • To what extent do moves appear to result in women dropping out of care, or in treatment interruptions? • Or, do women migrate for the purpose of accessing care, e.g. when they fall ill? Once they improve, do they return to areas of origin, or permanently relocate within the destination? • What would make it easier for them to access and remain in care in their destination place?
<p>Among both migrant and highly mobile women: other factors affecting enrollment and engagement / retention in care</p> <ul style="list-style-type: none"> • What other factors (e.g. negative experiences with providers, issues of stigma and disclosure, money or transportation problems) affect the degree to which they are able to access and remain engaged in care?
<p>Among those ever enrolled in care (quantitative measures to pilot-test)</p> <ul style="list-style-type: none"> • No. of migrations since diagnosis; no. of migrations since enrollment in care & treatment; no. of ART programs used to access care since diagnosis; no. of missed appointments at ART programs; no. of missed dosages

The findings of this study will be used to develop guidelines for improved clinical practice in HIV care with highly mobile patient populations, and for enhancing biomedical HIV prevention interventions.

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